

FALL 2018

CREATE YOUR LEGACY

Of Adding Tomorrows



“His resilience,
and my hopes for
his future, keep
me inspired.”

—Arathi, Arjun’s mom

Arjun is a resilient 4-year-old boy with a rare form of cystic fibrosis. Read Arjun’s story on page 3.

ALSO INSIDE

JEN WEBER’S
COMMITMENT TO
LIVING IN THE MOMENT

YEAR-END TAX BREAK
OPPORTUNITIES

AND MORE



LEGACY GIVING
YOUR GIFT ADDS TOMORROWS

A COMMITMENT TO LIVING IN THE MOMENT

MEET JEN WEBER, J.D.

Jen Weber loves to play cello, travel, and do anything that gets her outside on a sunny day. She hasn't let CF or either of her two double-lung transplants stop her from doing what she enjoys. Today, Jen is thriving and working at the age of 44.

Jen has a "YOLO" tattoo, which in many respects embodies her outlook on life. "YOLO is about living life to the fullest," Jen says. "Not that I need to be reminded that 'you only live once,' but when I see it, I am reminded of soaking up the present, of enjoying every moment, right now." Jen notes that she can live life to the fullest due in part to the security she has found in planning for the future.

"From a young age, I was planning around breathing treatments and pills. Much like I turn to the CF clinic (and now my transplant

In her planning for the future, Jen has designated the CF Foundation as a beneficiary of her retirement plan.

team, too) for plans to support my health when I am doing well, I recognize that planning remains

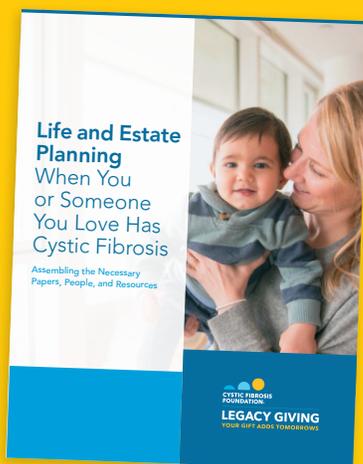
essential in all parts of my life."

Planning has helped her accomplish her goals of going to graduate school, pursuing a career, and traveling. As part of her planning, Jen prepared her estate plan and designated the CF Foundation as a beneficiary of her retirement plan. In doing so, Jen has communicated her values and dreams for a better future for all those with CF.

Leaving a gift to the CF Foundation in your will, trust, or by beneficiary designation can strengthen your commitment to helping people with CF, like Jen, live full, productive lives now and in the future.

"I AM PLEASED TO SHARE THIS NEW RESOURCE FROM THE CF FOUNDATION."

— Jen Weber, J.D.



Download your complimentary copy today at www.cff.org/legacygiving.



Jen Weber, J.D., made planning for a long, healthy life a priority in her twenties, despite the uncertainty of her future with CF. Now thriving at age 44, she is grateful that she planned ahead.

ARJUN'S RESILIENCE AND HUMOR

IN THE FACE OF CYSTIC FIBROSIS

Arjun was born early with a rare mutation of cystic fibrosis. He recently turned 4 years old, and he has already had nine intestinal surgeries. In total, he has spent more than 6 months of his short life in the hospital.

Yet, Arjun's mom, Arathi, says "you'd never know by looking at him, that he's been through so much." Despite his struggles with CF, Arjun has remained a resilient kid, and his personality is infectious. "He's the one who lifts our spirits when he's in the hospital. He's always joking with us and his care team, bringing a smile to their faces."

Arjun leads a pretty normal, active life. In addition to attending preschool, he has taken up gymnastics and swimming. While Arjun focuses on 'living today,' Arathi and her husband, Charlie, can't help but think about his future.

"We hope for a long, healthy life for Arjun," Arathi says, "and we know we are not in this fight alone. There is hope on the horizon for new treatments that can help people with rare CF mutations like Arjun, and we're confident that one day there will be a cure for all people with this disease."

Charlie (dad) and Arathi (mom) bring Arjun to gymnastics, swimming, and the local park to help him stay active and healthy.



NEW HOPE FOR NEW LUNGS

THE CF FOUNDATION'S LUNG TRANSPLANTATION INITIATIVE

The CF Foundation has made incredible progress in CF research and care, but many people with CF still face the possibility of a lung transplant. Lung transplantation can extend and improve quality of life, but there are many risks to consider.

Targeted at addressing such risks, the CF Foundation has developed the Lung Transplant Initiative – a \$15 million, multiyear initiative to enhance the delivery of lung transplant clinical care, increase understanding of post-transplant complications, and help advance new therapies for lung transplantation through clinical trials.

Through this initiative, a consortium of 10 transplant centers are working to define and implement best practices, better understand rejection, and develop new therapies. The Foundation is additionally providing transplant-specific independent research grants and is collaborating with other organizations to optimize organ allocation.

"We are committed to improving the lung transplantation experience for people with cystic fibrosis and their families, and helping those who do require transplantation to live longer, healthier lives," says Michael Boyle, M.D., senior vice president for Therapeutics Development at the CF Foundation.

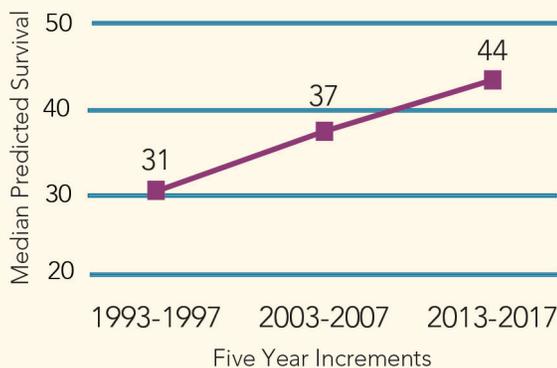
2017 PATIENT REGISTRY HIGHLIGHTS

THE LATEST TRENDS IN CARE AND
RESEARCH

44 YEARS
2013-2017

Among people with CF born between **2013** and **2017**, half are predicted to live to **44 years old or more**. This does not reflect individual variability in survival seen among people with CF.

SURVIVAL



People with CF continue to enjoy longer and healthier lives. Life expectancy estimates do not yet account for the potential benefits of newly available CFTR modulators and other recent clinical care improvements.

Visit www.cff.org/PatientRegistry to see the full 2017 Patient Registry Highlights Report and much more.

RECEIVE A TAX BREAK WHILE ADDING TOMORROWS

IRA QUALIFIED CHARITABLE
DISTRIBUTIONS

More and more, CF Foundation donors age 70½ and older are using a qualified charitable distribution (QCD) from an IRA to make tax-wise gifts ranging from \$100 to \$100,000 every year.

What is a QCD?

- A QCD from an IRA is a convenient, tax-efficient way for donors who are at least 70½ years old to support the CF Foundation directly from a traditional IRA or Roth IRA

What are the advantages?

- You pay no income tax on the gift
- You benefit even if you do not itemize your deductions
- Your gift counts towards your annual required minimum distribution
- The transfer process is quick and requires minimal paperwork

How to give from an IRA?

- Contact your advisor to see whether a QCD from an IRA is a good option for you and, if needed, provide our Tax ID number: 13-1930701
- Notify us that the gift is on its way by contacting your local chapter or Tricia Benson at 240.482.2845 or tbenson@cff.org

Tax treatment of this contribution is subject to IRS regulations, please contact your advisor for guidance based on your individual situation.

CONTACT US TO LEARN MORE

Tricia Benson, Senior Director of Planned Giving
240-482-2845 | tbenson@cff.org

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YOUR GIFT ADDS TOMORROWS

This information is not intended as legal, accounting or other professional advice. For assistance in charitable planning, always engage the services of a qualified professional.